We are very pleased to have our Division of Medical Ethics and Humanities Associate, Maureen Henry, return to Utah. Here she shares with us her experiences of the past year:

I spent the past year as a Health and Aging Policy Fellow in the office of Senator Mark Warner (D-VA) at the intersection of policy, medical practice, ethics, and law. The fellowship, funded by the Atlantic Philanthropies, provided me with the training and financial support necessary to live and work in Senator Warner’s Washington office.

Senator Warner had a long-standing interest in older adults and in decision-making for patients with serious illness. He introduced his first version of Senior Navigation and Planning Act in the Senate shortly before Sarah Palin labeled similar legislative efforts “death panels” during the 2009 health care reform debate. My role in the office, beginning in early 2013, was to bring my experience and a new evidence base to the legislation about efficacy of different mechanisms for documenting decisions and the elements needed to help patients understand their treatment choices. The goal of the newly-titled Care Planning Act of 2013 was to align the care people choose with the care they receive. I had a similar role in Utah, where I facilitated the process of transforming Utah’s Personal Choice and Living Will Act into the Advance Health Care Directive Act.

My Utah experience was helpful, but policy levers are different when addressing these issues at the federal level. State law governs health facility and provider licensing, surrogate decision-making for adults with impaired decisional capacity, and advance directives. But the federal government controls Medicare and Medicaid law and policy.

Medicare and Medicaid “conditions of participation” (COPs) have tremendous influence on the care delivered to patients at the bedside. The Patient Self Determination Act (PSDA) is part of COPs. This is the source of the question from admissions clerks who ask people registering at a hospital, “Do you have a living will or advance directive?” The Care Planning Act brings the PSDA to a more mature level, requiring providers to offer assistance in completing directives, to put a copy of directives in the medical record, and to honor the best evidence of the patient’s preferences, whether documented in an advance directive, a POLST form, or in notes from an office visit. The last provision does not provide black and white guidance to providers, but the reality of medical decision-making for seriously ill individuals is not black and white.

The bill would also provide reimbursement for a care planning process. The Planning Services benefit would reimburse providers for a multi-disciplinary, possibly multi-encounter process that provides patients with information about their diagnosis and typical disease trajectories, a goals of care discussion, exploration of how relevant treatments would or would not help the patient to achieve care goals, and appropriate documentation of the plan.

Welcome to Jacob Stegenga, PhD.

Our newest Division of Medical Ethics and Humanities Faculty Member!

Jacob Stegenga joins us from the Department of Philosophy at the University of Utah where he is Assistant Professor. His area of research is philosophy of science, including methodological problems of medical research, conceptual topics in evolutionary biology, and fundamental issues in reasoning and rationality. A native of Victoria (Canada), Stegenga completed his Ph.D. in philosophy at the University of California, San Diego, and a postdoctoral fellowship at the University of Toronto. Prior to completing his Ph.D. he worked as an epidemiologist for the Public Health Agency of Canada. Details about his research can be found on his website: individual.utoronto.ca/jstegenga.
On January 16, 2014, the Division of Medical Ethics and Humanities hosted a panel discussion, “How We Perform, Understand, and Learn from Stories of Health Care in Utah,” in which panelists shared experiences that highlighted several themes Anna Deavere Smith acted out the night before in her 2014 David P. Gardener Lecture in the Humanities and Fine Art presentation, “Health Care: The Human Story.” Sam Brown, Assistant Professor of Pulmonary and Critical Care Medicine, spoke of 30-60% of ICU survivors with PTSD, suffering with false memories of being undead, tortured, or raped. He and colleagues are studying how narrative and ICU diaries might help to overcome delusional memories of life-threatening illness, and prevent PTSD. Joni Hemmond, Assistant Professor of Pediatrics and Medical Director for the Teen Mother and Child Program/Teen Health Clinic, shared a program where residents interview teen actors, who, along with a group of observing teens, provide feedback to residents. They have learned, importantly, that teens appreciate interviewers inserting personal pieces, and try to learn about them as people. Sarah Nae’ole, manager of ARUP Labs employee health clinic and previous Practice Coach and QI specialist for the Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ), along with Sydney Cheek O’Donnell, Assistant Professor in the Department of Theater, and Chuck Norlin, pediatrician and Director of UPIQ, shared how Forum Theater has clarified problems with anxiety, ADHD, and depression. Unlike the academic analysis that occurs in using case studies, Forum Theatre scenarios act out visceral and emotional elements, and leave problems unresolved. Observers then suggest improvements to address these problems. Antoinette Laskey, child abuse pediatrician and Chief of the Division of Child Protection and Family Health and Medical Director of Safe and Healthy Families, shared how helpful it has been to use actors to educate healthcare workers on sensitive evaluation of suspected child abuse, and for infant death scene investigation training with law enforcement, death investigators, and child welfare workers.

Anna Deavere Smith emphasized that underlying all of these shared experiences is the question, “What needs to be brought forth from people to help with their healing?” If physicians remain in doctor-patient roles, they dodge this question. But our goal is to have healing communities; For this, patients need to want to participate in their care. Physicians should not assume that patients want to see them but need to develop rapport with them. She asked, “Why is skill and excellence too often accompanied with rudeness?” In her extensive interviews patients spoke repeatedly of rudeness in the doctor-patient setting. Does the doctor care, for example, that the people out front are rude? Why shouldn’t patients ask their anesthesiologists about drugs? The need is not about having social graces, ie “being nice,” but about listening to perceive what patients really need. In short, it’s about changing some dominant narratives within the culture of say, doctors not listening to anything a patient says beyond the first 20 seconds!

Creating Healing Communities: The DMEH Panel with Anna Deavere Smith: “How We Perform, Understand, and Learn from Stories of Health Care in Utah” By Linda Carr-Lee Faix

Gretchen Case presented Grand Rounds for the Department of Internal Medicine on January 23, discussing "Exploration of Ethics Through Theater: George Bernard Shaw's 'The Doctor's Dilemma' 100+ Years Later." The recorded version of this talk can be accessed through the Internal Medicine website. https://medicine.utah.edu/internealtmedicine/grand_rounds.php On February 14, she will present on the arts and humanities in medical education at a symposium near Washington, DC, held by the American Medical Students Association. On February 24 at 2:30p, she will be interviewed by Harriet Hopf on Scope, which is the new in-house radio station for the Health Sciences Campus. Case and Hopf will discuss the recent visit of Anna Deavere Smith and the place of theater and performance in medical education. http://healthcare.utah.edu/the-scope/?id=13274732&page=2

Peggy Battin gave the keynote talk at a conference convened by the Center for Practical Bioethics, "The State of Palliative Care Across Settings," Washington DC, January 29. Peggy also presents a paper for a workshop at the Centre for Ethics, University of Zurich, Switzerland, Feb. 4., "Dignity and Rights in Physician-Assisted Dying," and with Kirtly Jones, MD) presents "The Science and Ethics of Male Contraception" at the University of Florida, Coral Gables, March 17. She will speak at the Center for Practical Bioethics, Kansas City, April 25.

Jim Tabery presented (or will be presenting) "Of Dogs, Daycare, and Discipline: A 'Genetic Guide to Parenting?" at the University of Arkansas for the Medical Sciences, January 7, at the University of Utah in the Foundations of Personalized Healthcare program, January 27, at Washington University at St. Louis, February 5, and at the American Philosophical Association, April 16.

Leslie Francis presented “Of Hippa and Gina: Legal Projections applicable to the Use of Data in Personalized Medicine,” in the Foundations of Personalized Healthcare program at the University of Utah, on January 27. She also spoke on “Hard issues in end of life decision-making,” for St. Mark's Hospital ethics committee, January 15, and on February 7, will be speaking on “Sharing medical records with adolescents who are terminally ill,” at the Michigan State University Journal of Medicine & Law Symposium on Living With Terminal Illness: should adolescent minors make decisions at the end of their life? She will present at the APA Central Division meeting, Symposium on Reproductive Ethics, in Chicago, on February 28 on "Reproductive Technologies in Contexts of Injustice."

Sam Brown’s Through the Valley of Shadows: Making Intensive Care Human is now officially under contract with Oxford University Press. It will be forthcoming probably in early 2016. Sam is also lecturing as part of a course for the Osher Institute that explores problems with current advance directives.

Susan Sample presented at the National Communication Association annual conference in Washington, D.C., Nov. 21 "So Let's Talk Theory: Picking Up the Narrative Thread in Health Communication Conversations." She also has been invited to present at the Conference on College Composition and Communication in Indianapolis, March 19, "Dying Bodies as Kairiotic Sites for Suturing Rhetorical Theories of Silence and Material Rhetoric."
We have several Evening Ethics discussions planned, any and all of which we hope you will join us to engage in interesting, provocative, informed discussions. All sessions will be held in Research Administration Building’s first floor conference room, 5:30pm-7:00 pm, and CME and light refreshments will be available.

“Re-thinking Braindeath: Questions Raised by Current Cases in the Media” (Wednesday, February 12, 2014)

The New York Times reports, "Jahi McMath was declared brain-dead after complications from surgery on Dec 9 and Children’s Hospital Oakland wanted to remove her from a ventilator. But her heart continued to beat, and her family protested the removal in court, so she has remained connected to the machine.” Are Jahi’s parents simply unwilling to accept the fact of death in their child or does their refusal to let go reflect a more fundamental problem with the notion of brain death? Are people who have lost whole brain function really dead? If so, why?

This Evening Ethics discussion will briefly review this case, and perhaps a very similar case at Primary Children’s Hospital, to explore the medical and philosophical foundations of the determination of death. Three articles to prepare for this session:

http://www.nytimes.com/2014/01/04/us/a-brain-is-dead-a-heart-beats-on.html?_r=0
http://medicine.utah.edu/internalmedicine/medicalethics/activities/ethics/2014.php#February

"Ethical Issues in Evidence-based Medicine" with Alex Kemper, MD, MPH, MS
2014 David Green Memorial Speaker (Wednesday, March 5, 2014)

Dr. Kemper is a pediatrician at Duke Medical Center. His research focuses on improving the quality of care that children receive by strengthening the linkages between primary care, specialty care, and public health services. Stay tuned for more details on this Evening Ethics soon!

“Moral Fictions in End of Life Care” with Dan Brock, PhD,
2014 Max and Sara Cowan Memorial Speaker (Wednesday, March 26, 2014)

Dr. Brock is the Frances Glessner Lee Professor of Medical Ethics, Department of Global Health and Social Medicine, Division of Medical Ethics, Harvard Medical School. He will facilitate a discussion on Moral Fictions, details forthcoming.

“Medical Nihilism, Today?” facilitated by Jacob Stegenga, PhD (Monday, April 7, 2014)

Medical nihilism—the thesis that we should have low confidence in the effectiveness of medical interventions—was expressed by the ancients (Heraclitus, Virgil, and Hippocrates), early moderns (Shakespeare, Dryden, Montaigne, and Molière), and by prominent physicians in the nineteenth century. With the discovery of insulin, antibiotics, and other effective medicines, medical nihilism fell out of favor by the middle of the twentieth century. In the last decade, however, many physicians, epidemiologists, and journalists have begun expressing views like medical nihilism. For instance, Marcia Angell claims that “only a handful of truly important drugs have been brought to market in recent years” while the majority are “drugs of dubious benefit.” Or consider the article by John Ioannidis, the most-viewed article of PLoS Med: “Why Most Published Research Findings Are False”. A prominent article by Ben Goldacre last year was simply titled “The Drugs Don’t Work”. This new wave of medical nihilism focuses on overdiagnosis and overtreatment, widespread bias in research, and the low effectiveness of widely prescribed classes of drugs as reported by recent clinical trials and meta-analyses. What should we make of this new medical nihilism? Are recent drugs as ineffective as Angell and others claim they are? What changes to the broader context of medical research can be made to address the problems articulated by this new wave of medical nihilism? Dr. Stegenga will provide background; there will be no prior background reading needed for this session.
Physicians Literature and Medicine Discussion Group
Upcoming Physicians Literature and Medicine programs, 6:00-8:30pm,

February 5, 2014    LDSH Pugh Boardroom    Facilitated by Aden Ross, Ph.D
The Daughters of Mars by Thomas Keneally

The Daughters of Mars, by Thomas Keneally, follows the lives of two sisters from Australia, both nurses who enlist to serve on the European front during WWI. It is a novel of extraordinary scope and depth, dramatizing the war from the unusual perspective of Australia’s contributions to the Great War, both in battle and in medicine. Keneally, best known for his novel Schindler’s List, vividly describes a wide range of sympathetic individuals attempting to survive everything from primitive aerial bombardment to mustard gas to the Spanish flu, all while dealing with lack of supplies, diminishing medical staff and overwhelming casualties. He portrays the larger effects of war as well—its devastation on the emotional, physical, psychological and familial well-being of an entire generation. Meanwhile, the Durrance sisters and their friends all desperately try to find or keep whatever human bonds they can under conditions as random as they are violent. Apart from providing a solid background about medicine in WWI, the novel contains excellent, page-turning descriptions. Keneally’s creation of the sinking of a hospital ship is about as gripping as writing gets.

March 5, 2014    LDSH Pugh Boardroom    Facilitated by Susan Sample, MFA
Pulse--Voices From the Heart of Medicine: More Voices: a second anthology
edited by Paul Gross MD and Diane Guernsey

By request, we will read the second anthology of stories and poems that originally appeared in the online journal, Pulse--Voices from the Heart of Medicine. These short narratives share with the first anthology the overall theme of the “giving and receiving” of health care, but the authors featured and the topics focused upon in this second book cover a wider range. A virologist in India describes a poignant hospital scene she witnessed, while an American physician who wrote prostate cancer screening recommendations tells of unexpected emotional responses. Domestic violence, prescription addiction in the elderly, and homelessness are new topics sensitively dealt with. More Voices, as the title suggests, also includes more narratives: twenty one months’ worth. You may read them in chronological order, or consult indexes at the end, which group the pieces by subject and genre, and provide a one-sentence summary. For our discussion, I’d suggest selecting two narratives written by someone who shares your perspective (for example, if you’re a pediatrician, a poem by a pediatrician) and another two written by someone whose perspective you do not share (if you’re a nurse, a story by a family medicine resident). We’ll open with “Ladies in Waiting” that begins on page 179.

March 19, 2014    University of Utah Hospital Large Conference Rm  #W1220
Facilitated by Gretchen Case, PhD, with Geoffrey Tabin, MD
Second Suns: Two Doctors and Their Amazing Quest to Restore Sight and Save Lives by David Relin

Second Suns is the nonfiction account of pioneering cataract surgery in Nepal by two ophthalmologists, Sanduk Ruit and Geoffrey Tabin. Together they founded the Himalayan Cataract Project in 1995 and have developed inexpensive lenses and surgical procedures that can effectively cure blindness due to cataracts for less than $25. David Oliver Relin, the author of Second Suns, has been widely cited not only for his compelling storytelling but for his honest appraisal of the project and its two founding physicians. Dr. Tabin, who practices here at the Moran Eye Center, plans to join us for our discussion of the book.

April 2, 2014    LDSH Pugh Boardroom    Facilitated by Rachel Borup, PhD
Raising Henry: A Memoir of Motherhood, Disability, and Discovery by Rachel Adams

Hard work, ambition, and intellectual acuity had paid off for Rachel Adams. With a tenured position in the English Department at Columbia University, a successful husband and an adorable first son, her life had gone very much according to plan. However, moments after her second son, Henry, was born, she experienced the shock of her life when her doctors told her that her baby had Down Syndrome. In Raising Henry: A Memoir of Motherhood, Disability, and Discovery, Adams recounts the crash course in living with disability she and her family experienced over the first three years of Henry’s life. With humor and honesty, Adams uses her own family’s experiences to engage with larger debates about disability in our society, including the roles of prenatal testing and genetic counseling.
A year in Washington D.C.: Helping Older Adults with Healthcare Planning

The elements of the benefit are not innovative; they are the elements of a quality informed consent process. It is my personal hope that if the Care Planning Act becomes law, the process of informed consent in all patient encounters will be favorably influenced by the explicit structure of the process required by the Planning Services benefit.

In the drafting process we grappled with many of the most controversial ethical challenges in medicine. The process was sometimes difficult, but the end product is a bipartisan bill that reflects a thoughtful and practical balancing of competing concerns and interests, guided by evidence about what patients need.

I left Washington in November with a deep admiration for Senator Warner and Senator Johnny Isakson (R-GA), the bill’s original co-sponsor. They introduced a bill addressing one of the most ethically sensitive and politically volatile policy areas being addressed in Congress because it was the right thing to do for patients and their families.
Our 2014 David Green Memorial Speaker will be Alex Kemper, MD, MPH, MS. Dr. Kemper is a pediatrician practicing at Duke Medical Center and the deputy editor of Pediatrics. In his David Green Memorial Lecture, “Peer Reviewed Publication: Lessons from Pediatrics,” he promises to “reveal the inner workings of the journal and also to discuss some real-life ethical cases and how we resolved them.” Please join us on March 6, 2014, 8:00am, PCMC 3rd Floor auditorium for this special Pediatric Grand Rounds that honors past Division of Medical Ethics and Humanities Faculty member, David Green, MD. Please join us, as well for Dr. Kemper’s Evening Ethics Discussion the previous evening, March 5, 2014, 5:30-7:00pm, Research Administration Building, 1st floor large conference room.

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Our 2014 Max and Sara Cowan Memorial Speaker will be Dan Brock, PhD. Dr. Brock is the Frances Glessner Lee Professor of Medical Ethics, Department of Global Health and Social Medicine, Division of Medical Ethics, Harvard Medical School. There will be three opportunities to hear Dr. Brock:

- Internal Medicine Grand Rounds, on Rationing, March 27, 2014, 7:45 am, HSEB 1750
- Cowan Memorial Public Lecture, “The Future of Bioethics-From Clinic to Population” March 27, 2014, 12:30 pm, HSEB 2600
- Evening Ethics, “Moral Fictions in End of Life Care” March 26, 2014, 5:30 pm, RAB 117